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Original Article

Strategies for recruiting a sample of adults with type 2 diabetes from primary care clinics in rural Appalachia: Incorporating cultural competence

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ABSTRACT

Background: Recruiting research participants from primary care in rural Appalachia is a major challenge and can be influenced by cultural characteristics, making it critically important to incorporate strategies of cultural competence in the overall design of clinical research.

Objectives: The purpose of this paper is to describe culturally competent strategies used for recruitment and data collection with a sample of adults with type 2 diabetes from primary care settings in Appalachia.

Design: The Purnell model of cultural competence and relevant literature served as a framework for study design. Four overarching approaches informed the organization of recruitment strategies and development of the data collection plan.

Procedures: The approaches included selection of research sites, establishing collaborations, sustaining collaborative relationships, and enhancing understanding of benefits of participation. Four recruitment sites were selected based on potential to enhance diversification of participants; multiple steps were included in each of the three remaining approaches to build relationships and gain participation. A study log was maintained to provide evaluation data.

Results: Recruitment took 14 months and a sample of 102 subjects provided consent with 101 participants providing complete data. Demographics were representative of the region except that African American participation was higher (6.9%) compared to current north central Appalachia (3%). Over 72% of participants indicated they would be interested in participating in future studies.

Conclusions: These findings emphasize the importance of employing strategies for cultural competence in study design. Use of concepts from the Purnell model led to enhanced representativeness and potential for subsequent generalizability.

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1. Introduction

Recruiting research participants in primary care is a major challenge in clinical research [1], [2]. Limited resources exist to successfully guide participant recruitment in primary care research [3] and are mainly focused on recruitment of participants in academic settings for clinical trials [4]. Published literature of recruitment efforts in clinical trials reports that most research trials neither successfully recruit the planned sample size nor do so in the

expected timeframe [5], [6]. Reasons include lack of resources such as time, staff, and training [7], lack of researcher credibility in the primary care culture [8], and concerns about the impact on the relationship between the potential participant and the provider of care [1].

Many additional challenges exist when trying to recruit from rural Appalachia. The Appalachian region is a 205,000-square-mile region that follows the Appalachian Mountains from northern Mississippi to southern New York. Appalachia is a federally designated region characterized by socioeconomic and environmental factors, including low income, low education, potentially limited health literacy, lack of access to healthcare, challenging geography, and being largely rural [9]. These factors not only influence the burden of health disparities prevalent in this region [10] but also

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influence recruitment into research studies [11]. These challenges are similar to those of other underserved, marginalized, and minority populations [2] [12], [13], thus emphasizing the need for recruitment strategies that take into account cultural characteristics of unique study populations.

1.1. Background

Appalachian culture has been largely influenced by a historical context of geographic isolation and exploitation for natural resources and labor [14]. Often reluctant to seek support beyond the immediate community, Appalachians first turn to extended family, then church, then community [14]. A mistrust of outsiders [13] [15], general lack of assertiveness, and fear of being taken advantage of by the healthcare system influences their participation in healthcare [16] [17], and often ends up with Appalachians not coming to clinic for care [18]. In addition, similar to other underserved populations, characteristics of Appalachian culture often include a general distrust of the medical community [2], and mistrust of research and health care providers [12], [13]. In addition, health literacy often presents as problematic in Appalachia. A population-level problem affecting nearly 9 out of 10 English-speaking adults in the United States [19], limited health literacy is strongly associated with disadvantaged populations [20], like Appalachia. Characteristics of the Appalachian population, including significant numbers of adults over age 65, people with less than a high school degree or GED, and people at incomes at or below the poverty level, increase the likelihood of the limited health literacy [19]. Twenty percent of West Virginians' struggle with low literacy levels, with as many as 40% of adults in certain counties not possessing basic literacy skills [21].

To successfully recruit participants and conduct research in the Appalachian region, the research design needs to demonstrate a culturally competent approach. Cultural competence in healthcare refers to providers having the knowledge, understanding, and skills of a cultural group to provide acceptable care [22]. Cultural competence in research is an understanding of the cultural characteristics of study participants and the expression of that understanding in the design, conduct, and interpretation of the research [23].

1.2. Purpose

The consequences of poor recruiting can include an extended length of the study, delayed dissemination of findings, increased costs, increased workload [24], and ultimately can result in an under-powered study with threats to internal and external validity [6]. Thus, strategies that are responsive to cultural issues are needed so that participation is increased. The purpose of this paper is to describe strategies to recruit and collect data on a convenience sample of adults with type 2 diabetes from primary care settings in the Appalachian region of north central West Virginia. The approach to developing these strategies was guided by a cultural competence model.

1.3. Guiding model

The model guiding this approach was the Purnell Model for Cultural Competence [25]. The purpose of this model is to provide an organizing framework for learning the concepts and characteristics of culture. The model views the individual, family, and community within their unique culture, and provides defining and interrelating characteristics of culture, and a structure for analyzing culture. The organizing framework consists of twelve domains and their concepts for assessing cultural attributes. The structure of this

framework can be used in any setting and applied to a broad range of observations or experiences. The model is based on an assumption that learning culture is an ongoing process, and that this process is non-linear, ranging from unconsciously incompetent to unconsciously competent.

Of the twelve major domains of culture, eight had high relevance when developing the recruitment and data collection plan for this study: health care practices, health-care practitioners, overview/heritage, communication, family roles and organization, workforce issues, bio-cultural ecology, and high-risk behaviors. Strategies were developed that were congruent with cultural characteristics of the Appalachian culture, facilitating a culturally competent approach when conducting research.

2. Methods

The recruitment plan described in this paper is from a completed and published descriptive study examining the relationships between diabetes-related distress, appraisal, coping style, and self-management [26]. The goal of the plan was to recruit and gather complete data on a convenience sample of 100 adult subjects with type 2 diabetes from rural Appalachia. For details of that study, including funding source, design, methods, human subjects and ethical clearance from an internal review board, and results, the reader is referred to Carpenter RD et al., 2017 [26].

2.1. Design

Guided by the Purnell model of cultural competence, strategies for the recruitment and data collection plan were drawn from the literature on the topics of recruitment, retention, and Appalachian culture. While the literature is limited, successful strategies have been described. Based on this review, four approaches were identified to organize strategies and develop the plan. The first approach for recruitment focused on knowing characteristics of clinic site populations so that selected sites had the potential to provide diversity in the study sample; the following three approaches focused on building and maintaining relationships with clinical sites and providing information about benefits to participation.

Under the guidance of the Purnell model, characteristics of Appalachian culture were viewed as being embedded in the context of person, family, community, and global society. Unique strategies for operationalizing components of the model and for recruitment were then developed to enhance the cultural competency of the project. The study team selected study variables based on specific characteristics identified in the Purnell model as being integral to that specific domain of culture. Subsequently, recruitment strategies were also developed that incorporated knowledge of culture in Appalachia.

Variables were assessed in respect to the following eight domains of the model: health-care practices, healthcare practitioners, overview/heritage, communication, family roles and organization, workforce issues, biocultural ecology, and high-risk behaviors. Health-care practices were assessed by collecting data on medication, mental health, distance to clinic, and ways of coping which includes spirituality. For healthcare practitioners, data was collected on collected gender and type of clinic attended. For Overview/heritage, data was collected about residence, socioeconomic status, education, and occupational status. With respect to communication and cultural consciousness, the team recognized the need to develop and maintain trust. This was operationalized by collecting dominant language and health literacy, in addition to implementing the strategies in the clinical sites that are outlined in Table 1. For family roles and organization, the team acknowledged

that it was important to know the ways of seeking support that are unique to people in Appalachia. Therefore, number of people in home, social, and marital status were collected. For workforce issues, data collection site and employment status were documented. For Biocultural ecology, skin color, height, weight, blood pressure, and A1C were collected. For high-risk behaviors, tobacco and alcohol use, and physical activity were collected.

It is important to note that in addition to the research participants, many of the clinicians and staff at the research sites were also from Appalachia. Thus a culturally competent design began in the proposal stage of the project with the research team. Research team members needed to acknowledge their own level of cultural consciousness while developing the recruitment and data collection plan. This was very important for research team members and those in the clinic sites to think about their own level of cultural competence and think about where they may be in terms of cultural consciousness. In order to facilitate this thinking process, key leaders on the research team studied the Purnell Model, cultural competence, and cultural consciousness. The team members openly discussed current perspective on cultural competence and consciousness and how it might impact recruitment and data collection.

In addition, the team recognized that health literacy could be problematic and potentially diminish recruitment and data collection success and, therefore, took steps to address health literacy. All questionnaires and study flyers were written at the sixth grade level, with the exception of a distress scale, which was written at the eighth-grade [27].

2.2. Setting

The geographic region where the current study took place was the Appalachian region of north central West Virginia. This area is comprised of approximately ten counties, all classified as rural [28], with the only metropolitan area consisting of two cities that lie 20 miles apart and have a combined population of 49,477 [29]. The population of this area is mainly Caucasian (Appalachia 90.8% and West Virginia 93.6%) with limited ethnic diversity [29]. However, demographic variations do occur, including diversity in age, income, education level, and access to care. Diversity of the people living within the sample may be captured through the selection of recruitment sites.

Four unique research sites were selected as a strategy capture the diversity of the potential participants from this geographic area. Each of these research sites operated with a unique care delivery model. The largest recruitment site was an academic medical center primary care family medicine clinic, which provided care to over 1000 persons with diabetes annually. The types of patients seen at this clinic included the “traditional” patient, with average demographics of the north central West Virginia area. Insurance providers are reflective of the general community, including commercial, Medicare, and Medicaid. Very limited numbers of uninsured persons attend this clinic setting.

A second site was a nurse-managed, primary care site in the community, which provided care to over 250 persons with diabetes annually. This clinic sees a higher percentage of Medicaid recipients than most physician-managed clinics (i.e., 50% Medicaid, 20% Medicare, and 30% commercial). Patients at this clinic were more likely to be disenfranchised from traditional medical care, suffer from multiple chronic conditions, and be part of a member of a specified community where “word of mouth” had brought them in. For example, care was provided for a large percentage of members of a particular church in north central West Virginia. In addition, this clinic cared for generations of the same families.

The third site was a free clinic that provides care to the

uninsured and cares for over 200 persons with diabetes annually. This group of patients tends to experience major challenges with social determinants of health (i.e., lower education, low income, higher percentage of those residing in public house or suffer homelessness).

The fourth site was a human performance lab, which provides exercise prescription for special populations with chronic medical conditions, as well as healthy individuals. Some participants have their membership fees reimbursed by their insurance company. While not a primary care setting, this research site provided health maintenance and health promotion services. Most clients that would benefit from physical activity have been referred by a primary care provider due to health issues. The lab has approximately 165 members, with 99% experiencing at least one chronic disease and approximately 35% with diabetes. This group in general is more engaged in their health and has insurance coverage.

2.3. Measures

The numbers of subjects recruited and status of data collection were tracked by researcher constructed spreadsheets. In addition, a plan for evaluating these strategies was implemented. This plan included a study log that tracked data on site location, how the participant heard about the study, who recruited the participant, and time to complete data collection. In addition, feedback from all involved in the study including study personnel, research site staff, and participants was encouraged.

2.4. Procedures: four recruitment strategies

The first strategy for recruitment was the careful identification of the research sites. This was followed by three additional strategies that laid the foundation for the procedures for recruiting the sample and collecting data. Each strategy is described with procedural steps summarized in Table 1.

2.4.1. Establish collaborative relationships with research sites

For this study, a collaborative relationship referred to the agreement between the researcher and the director of the research site about the purpose of the research and a willingness to share resources needed to accomplish the goals of the research project. Once established, this agreement was extended to clinicians and staff of each research site. Collaboration between researchers and clinicians and positive experiences between the researcher and the research site have been described as creating loyalty, which in turn helps in recruitment [36]. Thus, communication was fundamental to relationships with clinicians, staff, and research participants in the clinical setting. The research team actively engaged with community partners to diminish mistrust of the research that is known to be common in the region.

This process began with discussions about the purpose of the research, approaches for implementing the project at the clinical site, and communication approaches to the research site on progress and findings. The shared resources agreed upon in the collaborative relationship between the researcher and the research sites included knowledge, people, space, and time. Strategies used to work with these resources included recognizing the interdependence between the academic and practice setting, educating the clinical staff about the purpose and the methods of the research project, learning how the research site functions as a clinical agency, and individualizing the recruitment and data collection plan with each unique research site.

A thorough understanding of the circumstances and realities of delivering patient care in complex, hectic clinical environments, including the conditions that exist where and when interactions

Table 1
Recruitment strategies.

Goal	Goal Priorities	Rationale	Strategic Actions to Reflect Cultural Competence
Capturing Diversity of Sample	Select unique research sites from the geographic area	A common problem in research participant recruitment is that samples tend to be homogenous, with over representation of a particular group, usually Caucasians [30]. However, demographic variations do occur, including diversity in age, income, education level, and access to care [9], and may be captured through selection of multiple recruitment sites ^{a-m} .	The selection of the four unique research sites is a reflection of the awareness of the community and culture that was served by each clinic [29]. This awareness led to the selection of four sites that differed in patient population so that the study sample would be less homogenous and capture diversity in a limited diversity area.
Establishing Partnerships	Recognize interdependence between the academic and practice setting.	The researcher and the research site each have unique and essential contributions to research ^{c,g} . The research site brings in depth understanding of the patients, concerns about the research participation patient may have, and potential application of research to the practice setting. The researcher brings opportunities for the research site to gain experience and skill in planning and conducting research ^{b-e} . Recruitment is facilitated when clinical practitioners understand the value of the research, including clinical relevance to practitioners and patients [4], [31]. Engaging in discussions about research goals and strategies builds a collaborative relationship, and is recognized as essential for successful clinical research ^{c,e,g} [32]	The study team worked to acknowledge the expertise of the clinical site workers so that the project could be easily assimilated into the clinical site without intrusiveness or interruption. The team maintained respectfulness for the clinical site and understood that the clinical site could determine the inclusion of the team and the project. A sense of common purpose and trust was developed. These strategies demonstrated cultural consciousness of the team as they reaffirmed how clinical agency contributions enhanced the success of the research project.
	Educate clinical staff about purpose and methods of the research study.	Recruitment is facilitated when clinical practitioners understand the value of the research, including clinical relevance to practitioners and patients [4], [31]. Engaging in discussions about research goals and strategies builds a collaborative relationship, and is recognized as essential for successful clinical research ^{c,e,g} [32]	Knowing that the clinical staff may lack knowledge about research methodologies, the study team provided education about the project in a way that was appropriate for Appalachian culture. Study personnel met with clinic staff in person and discussed the importance of the study using narratives or stories from past research and experiences. The team was open to talking with the clinic staff about their prior experiences with research. This strategy demonstrated cultural competence by acknowledging the importance of narratives in Appalachia [16].
	Learn how the research site functions as a clinical agency.	Research can be perceived as an additional burden, competing for limited time with patients [32]. Taking time to know how the research site functions demonstrates valuing the work that each staff contributes to patient care. It shows an understanding of an organized system of care that holds patient care as the priority ^g . This provides the researcher with knowledge of how to implement the recruitment of subjects and collections of data so to minimize disruption of patient care. This also demonstrates a commitment to engage with the clinical setting as a researcher ^{c,e,g} .	It was essential to spend time in the clinic setting learning functional operations. Culturally competent clinicians and researchers spend time learning cultural beliefs, values, and behaviors that can influence practice and inform study designs [33]. This strategy of spending time enhanced the knowledge of the study team, thus improving the ability of the team to demonstrate respect for persons and ways of doing things as the project was implemented.
Sustaining Partnerships	Individualize recruitment and data collection plan based on clinical site.	Clinical staff are often the best recruiters for a research study [34]. Taking time to negotiate the recruitment plan demonstrates valuing the knowledge clinic staff have of the work they do and the clients served. It assures inclusiveness into the research process, including clinic staff expertise in the planning and implementing of research. Most importantly, it shows respect for the work flow and processes of the clinic and the commitment of the researcher to avoid interfering with patient care ^{c,e,g} .	Cultural competence requires for researchers to be able to adapt to diversity by being able to adapt to the needs and preferences of patients and clinical sites [33]. The study was implemented in four diverse sites with differing patient populations. The study team was able to negotiate best procedures for recruitment and data collection in each site, receive feedback frequently, and modify plans as needed.
	Planned open communication	Communication is the most basic, yet essential strategy in sustaining collaborative relationships. Reinforcing the purpose, benefits to practitioners and patients and their role in the research, and implications of participation is essential for maintaining engagement in research ^{c,e,g} [4], [32].	Document communication plan with research site, including desired information and frequency of communication. Knowing the cultural norms of Appalachia, study team members communicated with clinic staff regularly, maintained a first-name basis instead of academic titles, and adhered to a regular schedule of presence in the clinic.
	Nurturing agency personnel	Sustaining collaborative relationships involves nurturing research site staff. While there is limited support for the use of practitioner incentives for practitioner recruitment [4], appreciation for collaborative efforts should be recognized ^{c,i} .	Well-received expressions of nurturing in Appalachia include small gestures of hospitality and listening to life stories and experiences. The study team not only provided education to the agency personnel. The team listened to stories of past interactions with researchers, maintained an attentiveness to relationships, provided gestures of hospitality, and regularly expressed gratitude for the partnership.
Enhancing Understanding of Benefits of Participating	Role modeling recruitment	Researcher presence and accessibility throughout the study, along with recruitment efforts that assign greater responsibility to researchers rather than practitioners and clinic staff are associated with higher subject recruitment ^{c,g} [5] [35], [36].	The researcher role models cultural consciousness through behaviors in the clinical partner site. Through taking an active role in recruitment and data collection, the study team was able to role model the process.
	Emphasizing the purpose	Engaging participants in the learning process about the purpose of research is more influential on recruitment than when or who presents the information [37]. Making the research problem more understandable and meaningful to potential participants may increase recruitment to the study [37]. Participation in research studies has been shown to be mainly associated with matters related to trust, relevance, and perceived benefit to the individual and community ^{b,c,f,g} [11].	Cultural consciousness requires the use of strategies that allow for potential participants to truly understand the meaning of participating in a study. The study team actively engaged in providing language and literacy level appropriate explanations, followed by in-depth descriptions of the study purpose and goals and how study findings could be valued by individuals and community.

(continued on next page)

Table 1 (continued)

Goal	Goal Priorities	Rationale	Strategic Actions to Reflect Cultural Competence
	Offering an incentive	Offering a monetary incentive is common in research studies. Incentives have been shown to increase participation [38], and lead to sustained participation over time [4]. Research studies are typically not affected by small incentive payments, meaning that potential participants are not compelled to agree to study participation other than voluntarily for the benefits that may result from the research ^{d,e} .	The size of the incentive offered in this study was consistent with the team being culturally competent. The team recognized that people in Appalachia would not likely accept a large financial incentive but a small incentive of a \$20 gift card had the potential to be appreciated without producing a psychological conflict.
	Minimizing participant burden	Burden of participation, or the effort required to participate in a research study, has been identified as a concern from both clinical staff and potential participants ^{e,g} [32].	Appalachian culture focuses on individual function and productivity. Persons in Appalachia prefer efficiency and are not <i>laissez faire</i> about use of time. Knowing this, the study team minimized participant burden.

Purnell Model Concepts:

- ^a Primary and secondary characteristics.
- ^b Health-care practices.
- ^c Health-care practitioners.
- ^d Overview/heritage.
- ^e Communication.
- ^f Family roles and organization.
- ^g Workforce issues.
- ^h Biocultural.
- ⁱ High-risk behaviors.
- ^j Nutrition.
- ^k Pregnancy.
- ^l Death rituals.
- ^m Spirituality.

with research site staff occur is required. Prior research suggests that lack of communication can be viewed as lack of appreciation of contribution to the research [32].

2.4.2. Sustain collaborative relationships with research sites

Collaborative relationships require commitment. Commitments include the expectation of sharing expertise and time, and to understanding the objectives and work culture of each of the research sites. This mutual sharing and understanding is an ongoing process required for sustaining relationships. For this study the following strategies were used to sustain collaborative relationships with research sites: Planned communication, nurturing, and role modeling of recruitment.

2.4.3. Enhancing understanding of benefits of participating

While establishing and sustaining relationships with clinical agencies is essential in the planning of a recruitment and data collection plan, a research study will not be successful if the study is not attractive to potential participants. The following strategies were used to make the current research study attractive to potential participants from the four research sites: Emphasizing the purpose, offering an incentive, and minimizing the burden of participation.

3. Results

The purpose of this paper was to describe strategies that were planned and implemented in order to recruit and collect data on a convenience sample of adults with type 2 diabetes from primary care settings in the Appalachian region of north central West Virginia. Using these strategies, the following outcomes were obtained.

3.1. Sample size

The target sample size to run preliminary analyses of study questions was set at 100 participants. A total of 102 participants were recruited for the study and provided consent and completion of data collection instruments. The number of participants

recruited from each site was as follows: academic medical center primary care family medicine practice ($N = 52$), nurse-managed primary care site ($N = 17$), free primary care clinic ($N = 17$), and human performance lab ($N = 16$). The percentage of participants recruited from each site closely reflected the total numbers of persons with type 2 diabetes visiting those research sites.

3.2. Sample demographic

As described earlier, the population from which the sample was drawn is a homogenous population (93.6% Caucasian). However, diversity in the sample in terms of social and physical characteristics was as follows: Ethnicity (Caucasian 88.3%; Hispanic 2%; African American 6.9%); half were married/significant, half were single/widowed/divorced; education (less than high school 12.7%; high school/GED 34.3%; some college 25.5%; college graduate (18.6%); income (<20,000 54.9%; 20,000–50,000 30.4%; >50,000 11.7%); 37.2% of the sample had possible low or low health literacy (See Table 2 for sample characteristics).

3.3. Completion of data

In addition to the challenge of recruiting subjects, collecting complete data often presents as a challenge, especially in self-report data. For this study, the data was collected primarily by the primary researcher and three additional research team members. Out of 102 participants, only one had to be excluded from analysis due to the amount of missing data. Of the 101, missing data was due to the participant deliberately choosing not to answer the question asking age ($n = 2$), income ($n = 1$), and employment ($n = 1$). In addition, three participants had no HbA1c value due to refusal to have the blood work drawn at any time during their primary care visit(s). The time for participants to complete the surveys ranged from 12 to 60 min, with the mean time being 25 min.

3.4. Time frame

The planned time frame for the study was twelve months. Subject recruitment and data collection started on month 2 of the

Table 2
Study sample characteristics versus census of West Virginia and north central Appalachia.

Characteristic	Sample (%)	West Virginia (%)*	North Central Appalachia (%)**
Caucasian	88.3	93.6	93.4
Hispanic	2.0	1.5	1.2
African American	6.9	3.6	3.0
High School Graduate	87.3	85.0	82.5
Female	67.6	50.5	Not Available
Poverty***	54.9	18.1	18.0

Note: *[29], ** [39], ***Poverty based on 2 person household income < \$16,460 per annum.

funding period and continued for 14 months, thus running two months over the funding period. The recruitment and data collection during the two-month period at the end of the study was assumed by the primary investigator.

3.5. Maintain ability to have contact with participants

As part of the consent procedure, participants were asked if they would be interested in participating in future research studies. If a participant wanted contacted about future research projects, they were asked to indicate “yes” and to then provide contact information. Out of 102 participants, 74 (72.5%) indicated that they would like to be contacted and notified of future research studies and provided a telephone number, email, and/or address.

4. Discussion

The results of this work indicate that it is possible in Appalachia to accomplish sampling goals, collect complete data, and conduct meaningful research. By using a culturally competent approach, multiple recruitment strategies, and emphasizing partnership with clinical agencies, an adequate sample representative of the geographic area was recruited with complete data within a 14-month time period.

4.1. Cultural competence in recruitment

The result of this study add to the current body of knowledge on culturally competent research. The Purnell model, as an organizing framework, effectively guided the research team and clinic staff and clinicians in the primary care setting to plan and implement a recruitment and data collection plan that addressed cultural competence in research. Primary and secondary characteristics, and the domains of spirituality, nutrition, high-risk behaviors, and biocultural ecology were captured in the selections of four unique research sites, each with a unique panel of patients. Eight of the domains of model (health care practices, health-care practitioners, overview/heritage, communication, family roles and organization, workforce issues, bio-cultural ecology, and high-risk behaviors) informed the development of strategies congruent with cultural characteristics of the Appalachian culture.

The strategies in this study were in line with what is described as cultural competence in research. By developing strategies that showed an understanding of the cultural characteristics of Appalachians and the expression of that understanding in the design and conduct of the research project, the research team was able to meet recruitment and data collection goals of the study. A culturally competent team is essential for recruitment and data collection. It is important to note that in addition to study participants, this approach was inclusive of study personnel and clinical staff.

Diverse strategies were employed in this project to ensure the team was attentive to the nuances of Appalachian culture. An emphasis was on concepts of trust and communication.

Understanding the history of mistrust embedded with the culture, and the ways in which Appalachians give and receive information and advice served as a foundation to communication strategies used by the research team and the clinical agency. In addition, recruitment and data collection occurred at the clinic site, which is embedded in the culture of Appalachia. This was enhanced by research and clinical staff recruiting and collecting data that were part of and living in the Appalachian culture, and reflected the racial/ethnic composition of the target population. This approach is in line with what is recommended by scholars and professionals in the field of Appalachian studies: to practice respect for local knowledge, value community diversity, and collaborate between professionals, community groups, and individuals [40].

4.2. Multiple strategies for successful recruitment

Multiple strategies were developed to establish and sustain collaborative partnerships with research sites, and to enhance understanding of the benefits of participation. Multiple strategies across all stages of research has been identified as necessary to address the barriers and challenges to recruiting socially disadvantaged groups, including mistrust of research or researchers, fear of authority, lack of perceived benefits for self or community, and lack of understanding of research [41].

The recruitment strategies explained in Table 1 were used in this study and have been demonstrated to be successful in other primary care settings and in the recruitment of culturally unique populations. For example Reed and colleagues [1] used a systematic approach and accomplished a sample of 256 participants from five general practice sites. By embedding multiple recruitment strategies, they designed a recruitment plan that minimized the impact of the research on the daily functions of the practice site, were able to engage the practice site in the research, and made the research attractive to participants.

McFarlane [34] used collaborative and multi-modal research techniques for recruitment. By developing a systematic recruitment strategy that included minimizing patient wait time and honoring agency partnerships, they were able to recruit and complete six studies of abused women, with samples ranging from 144 to 1203. In addition, these studies demonstrated retention rates from 89% to 100% for 24 months.

In one rigorous systematic review of recruitment strategies in primary care, the involvement of practitioners was identified as the most effective recruitment strategy [4]. This includes involvement in the design and conduct of the research so that the research team can understand the care environment. Of the 66 articles in this systematic review, 16 noted the use of practitioners in study recruitment and how this strategy may optimize study recruitment.

In another study, Ramsey and colleagues [42] used multiple strategies, including mailing, media, posters, brochures, and referrals from clinic staff. They recruited a sample of over 9000 people, with over 45% being referred from either study staff, clinic personnel, or friends. Only 15% of the sample were enrolled from

the clinic waiting room, and only eight percent from paid advertising. In addition, a key to meeting recruitment goals was adjusting the recruitment plan for each clinic site based on the characteristics of the patient population at each unique clinical site.

4.3. Collaborative partnership with research sites

Emphasis on partnerships with clinical agencies and strategies focused on that partnership together advanced the cultural sensitivity and overall success of the project. It is important to note the lead role of the primary investigator in establishing and maintaining these relationships, as well as being actively involved in recruiting and collecting data at all research sites. Being present in the research setting to engage with clinical agency staff and research participants, role model recruitment and data collection processes, and being from the Appalachian culture contributed to trust building throughout the research project. Gaining trust and support from clinical staff, who in turn conveyed a level of trust to research participants, facilitated recruitment and data collection efforts. Consistent with more current literature, strategies to address the issues of mistrust of research or the researchers include establishing community partnerships and the inclusion of gatekeepers in the research plans [41].

While the research project described in this paper was a quantitative descriptive design, features of community-based participatory research (CBPR) were incorporated into study planning and design. Being more of an orientation than a method, CBPR involves lay people in the research process with the aim of combining knowledge to improve community health [43]. The study design incorporated both clinicians and staff to participate in recruitment, data collection, and in evaluation of the project. In addition, participants were invited to leave comment and to leave contact information for future research projects if interested in participating.

Researchers addressing health concerns in rural Appalachia have recommended community-based participatory research (CBPR) methods because it has shown promise in addressing health disparities [44], [45]. A national study of CBPR projects focused on cancer prevention identified that best practices of CBPR studies included alleviating mistrust, supporting integration of local cultural knowledge, and training investigators from communities [46].

5. Recommendations

Based on this experience and evidence from the literature, several recommendations for recruiting and data collection in primary care can be offered.

5.1. Cultural competence evident in the study design

A well-planned recruitment and data collection plan should be emphasized in the study planning period and embedded in the study design. Recruitment and data collection plans need to go beyond a series of steps laid out in the procedures sections of a proposal, or to be followed with a trial and error approach when recruitment plans are not progressing. Strategies should go beyond advertisements and researcher contact information to include the strategies for establishing and sustaining collaborative relationships with the research sites. Inviting others outside of academe to be part of the research team, and together planning and evaluating the research process can promote a culturally competent research project that makes research meaningful to potential participants.

5.2. Plan project timelines to reflect the challenges of recruiting

Project timelines need to reflect the challenges of recruiting in disadvantaged populations, such as Appalachia, where people and communities may be hesitant to participate in research. For disadvantaged groups, time needs to be budgeted to develop relationships, including their involvement in study design [41]. Plan time to work with the research team in planning a research project so that potential participants understand the research and find it meaningful.

5.3. Presence of an experienced recruiter

Be present and role model recruitment and data collection in the research setting. The first contact with potential subjects is the most important, and the level of experience of the recruiter can strongly influence recruitment and data collection success. Recruiter experience is more likely to increase recruitment success [47]. Budget time for the primary investigator to be present in the setting and role model recruitment and data collection.

6. Conclusion

A proactive approach, using many strategies, in planning and implementing recruiting in primary care can result in meeting study goals on recruitment and data collection. By investing time before, during, and after the study recruitment period, both researchers and clinicians can work collaboratively to achieve research and practice goals. Evaluating the strategies to recruitment provides valuable information about challenges of recruiting in primary care, and provides valuable data in developing recruitment strategies to overcome this problem.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijnss.2018.06.003>.

References

- [1] Reed RL, Barton CA, Isherwood LM, Oliver-Baxter JM, Roeger L. Recruitment for a clinical trial of chronic disease self-management for older adults with multimorbidity: a successful approach within general practice. *BMC Fam Pract* 2013;14(125):1–7.
- [2] Murphy M, Merenstein D. Grassroots campaign trail methods to recruit for clinical trials: recruitment lessons learned from trail to trial. *Clinical Medicine Insights* 2011;5:1–7.
- [3] Ward E, Bower P, Collier D, Delaney B, Graffy J, Kinmonth A, Miller J, Wallace P. Primary care research recruitment: a practical guide. Manchester, United Kingdom: National Institute for Health Research; 2010.
- [4] Ngune I, Jiwa M, Dadich A, Lotriet J, Sriram D. Effective recruitment strategies in primary care: a systematic review. *Qual Prim Care* 2012;20:115–23.
- [5] Bowers P, Wilson S, Mathers N. How often do UK primary care trials face recruitment delays? *Fam Pract* 2007;24:601–3.
- [6] Bowers P, Brueton V, Gamble C, Treweek S, Tudur Smith C, Young B, Williamson P. Interventions to improve recruitment and retention in clinical trials: a survey and workshop to assess current practice and future priorities. *Trials* 2014;16(15):399. <https://doi.org/10.1186/1745-6215-15-399>.
- [7] Gray RW, Woodward NJ, Carter YH. Barriers to the development of collaborative research in general practice: a qualitative study. *Br J Gen Pract* 2001;51(221):222.
- [8] Salmon P, Peters S, Rogers A, Gask L, Clifford R, Iredale W, Dorwick C, Morriss R. Peering through the barriers in GP's explanations for declining to participate in randomised controlled trials: a systematic review. *Fam Pract* 2007;24(3):269–75.
- [9] Appalachian regional commission. July 17, 2017. Retrieved from, <https://www.arc.gov/index.asp>.
- [10] Smith L, Valenzuela J, Ludke RL. Engaging rural and urban Appalachians in research using a community-based participatory research approach. *Prism: A Journal of Regional Engagement* 2012;1(1):3–17.
- [11] Gul RB, Ali PA. Clinical trials: the challenge of recruitment and retention of participants. *J Clin Nurs* 2010;19:227–33.

- [12] Spears CR, Nolan BV, O'Neill JL, Arcury TA, Grzywacz JG, Feldman SR. Recruiting underserved populations to dermatologic research: a systematic review. *Int J Dermatol* 2011;50(4):385–95.
- [13] Leach CR, Schoenberg NE, Hatcher J. Factors associated with participation in cancer prevention and control studies among rural Appalachian women. *Fam Community Health* 2011;34(2):119–25.
- [14] Cronin AF, Grimm S, Ruscello D. Team intervention in food selectivity in a medically complex child in rural Appalachia. *Occup Ther Health Care* 2009;23(3):207–25.
- [15] Loftin WA, Barnett SK, Bunn PS, Sullivan P. Recruitment and retention of rural African Americans in diabetes research: lessons learned. *Diabetes Educ* 2005;31(2):251–91.
- [16] Behringer B, Friedell GH. Appalachia: where place matters in health. *Prev Chronic Dis* 2006;3(4):1–4.
- [17] Behringer B, Mabe KH, Dorgan KA, Hutson SP. Local implementation of cancer control activities in rural Appalachia, 2006. *Prev Chronic Dis* 2009;6(1):A34.
- [18] Self-control Welch W. fatalism, and health in Appalachia. *J Appalach Stud* 2011;17(1–2):108–22.
- [19] U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion 2010; National Action Plan to Improve Health Literacy. Washington, DC: Author.
- [20] Ludke RL, Obermiller PJ, Jacobson CJ, Shaw T, Wells VE. "Sometimes it's hard to figure": the functional health literacy of Appalachians in a metropolitan area. *J Appalach Stud* 2006;12(1):7–28.
- [21] The Literacy Crisis in West Virginia." The Literacy crisis in West Virginia. <http://lvmpc.org/lvmpc.org/literacy-crisis-west-virginia>.
- [22] Giger J, Davidhizar RE, Purnell L, Harden J, Phillips J, Strickland O. American academy of nursing expert panel report: developing culture competence to eliminate health disparities in ethnic minorities and other vulnerable populations. *J Transcult Nurs* 2007;18(2):95–102.
- [23] Harvard Catalyst. Cultural competence in research. The Harvard clinical and Translational Science center; 2010. Retrieved from <http://catalyst.harvard.edu/pdf/diversity/CCRannotated-bibliography-10-12-10ver2-FINAL.pdf>.
- [24] Treweek S, Lockhart P, Pitkethly M, et al. Methods to improve recruitment to randomized controlled trials: cochrane systematic review and meta-analysis. *BMJ Open* 2015;3:1–24. <https://doi.org/10.1136/bmjopen-2012-002360>.
- [25] Purnell L. The Purnell model for cultural competence. *J Multicult Nurs Health* 2005;11(2):7–15.
- [26] Carpenter RD, Theeke LA, Mallow J, Theeke E, Gilleland D. Relationships among distress, cognitive appraisal, self-management behaviors, and psychosocial factors in a sample of rural Appalachian adults with type 2 diabetes. *Online J Rural Nurs Health Care* 2017;17(2) [xxx-xxx].
- [27] Readability formulas. The SMOG readability formula, a simple measure of gobbledygook. Retrieved from: <http://www.readabilityformulas.com/>.
- [28] West Virginia Department of Education. Urban/Rural Designation for West Virginia Counties and the E-rate discount matrix. Retrieved from: <https://sites.google.com/a/wvde.k12.wv.us/erate/training-information/training-updates/fcc-and-sld-numbers-needed-for-application/urban-rural-designation-for-west-virginia-counties-and-the-e-rate-discount-matrix>.
- [29] United States Census Bureau. Quick facts: selected population estimates July 1, 2016: West Virginia; Monongalia county, West Virginia; Morgantown city, West Virginia; United States. 2016. Retrieved from <https://www.census.gov/quickfacts/table/WV,monongaliacountywestvirginia,morgantowncitywestvirginia,US/PST045216>.
- [30] Sugden NA, Moulson MC. Recruitment strategies should not be randomly selected: empirically improving recruitment success and diversity in developmental psychology research. *Front Psychol* 2015;6(523):1–11. <https://doi.org/10.3389/psyg.2015.00523>.
- [31] Dormandy E, Kavalier F, Logan J, Harris H, Ishmael N, Marteau TM. Maximising recruitment and retention of general practices in clinical trials: a case study. *Br J Gen Pract* 2008;58(556):759–66.
- [32] Newington L, Metcalfe A. Researchers' and clinicians' perceptions of recruiting participants to clinical research: a thematic meta-synthesis. *Journal of Clinical Medical Research* 2014;6(3):162–72.
- [33] Kodjo C. Cultural competence in clinician communication. *Pediatr Rev* 2009;30(2):57–64.
- [34] McFarlane J. Strategies for successful recruitment and retention of abused women for longitudinal studies. *Issues Ment Health Nurs* 2007;28:883–97.
- [35] Jessiman W. 'To be honest, I haven't even thought about it' – recruitment in small-scale, qualitative research in primary care. *Nurse Res* 2013;21(2):18–23.
- [36] Campbell MK, Snowdon C, Francis D, Elbourne D, McDonald A, Knight R, Entwistle V, et al. Recruitment to randomised trials: strategies for trial enrolment and participation study. *Health Technol Assess* 2007;11(48):19–48.
- [37] Caldwell P, Hamilton S, Tan A, Craig J. Strategies for increasing recruitment to randomized controlled trials: systematic review. *PLoS Med* 2010. <https://doi.org/10.1371/journal.pmed.1000368>. Retrieved from, <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000368>.
- [38] Watson JM, Torgerson DJ. Increasing recruitment to randomized trials: a review of randomized controlled trials. *BMC Med Res Meth* 2006;6(34):1–9. <https://doi.org/10.1186/1471-2288-6-34>.
- [39] Pollard K, Jacobsen LA. The Appalachian region: A Data Overview from the 2010–2014 American Community Survey Chartbook. Retrieved from https://www.arc.gov/assets/research_reports/DataOverviewfrom2010to2014ACS.pdf.
- [40] Keefe SE. Appalachian cultural competency: a guide for medical, mental health and social service professionals. Knoxville, TN: University of Tennessee Press; 2005.
- [41] Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, Brozek I, Hughes C. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Meth* 2014;14(42):1–29.
- [42] Ramsey TM, Snyder JK, Lovato LC, Roumie CL, Glasser SP, Cosgrove NM, Olney CM, Tang RH, Johnson KC, Still CH, Gren LH, Childs JC, Crago OL, Summerson JH, Walsh SM, Perdue LH, Bankowski DM, Goff DC. Recruitment strategies and challenges in a large intervention trial: systolic blood pressure intervention trial. *Clin Trials* 2016;13(3):319–30.
- [43] Minkler M. Community-based research partnerships: challenges and opportunities. *J Urban Health* 2005;82(2):ii3–11.
- [44] Denham SA, Meyer MG, Toborg MA, Mandle MJ. Providing health education to Appalachia populations. *Holist Nurs Pract* 2004;18(6):293–301.
- [45] Schoenberg NE, Howell BM, Fields N. Community strategies to address cancer disparities in Appalachian Kentucky. *Fam Community Health* 2012;35(1):31–43.
- [46] Simonds VW, Wallerstein N, Duran B, Villegas M. Community-based participatory research: its role in future cancer research and public health practice. *Prev Chronic Dis* 2013;10(120205). <https://doi.org/10.5888/pcd10.120205>.
- [47] Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Publ Health* 2006;27:1–28. <https://doi.org/10.1146/annurev.publhealth.27.021405.102113>.